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**A Q methodological exploration of caregivers'
beliefs regarding their child's Asperger's
Syndrome**

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Doctorate in Clinical Psychology (DClinPsychol)

University of Edinburgh

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Overview of Thesis

This thesis follows a portfolio format and constitutes part-fulfilment of the academic component of the degree of DClinPsychol at the University of Edinburgh. The author has also completed three essays, four case studies and two small scale research projects over the course of the degree.

An abstract provides an initial overview of the portfolio thesis, including the aims, findings and clinical implications.

Chapter one presents a systematic review of published research investigating parental beliefs regarding their child's autism spectrum disorder and its effect on behavioural or psychological outcomes. The review was prepared and written in accordance with the author guidelines for submission for publication to the Review Journal of Autism and Developmental Disorders (see Appendix 1). For ease of reading, tables and figures are embedded within the text in single-line spacing, however, for journal submission these will be at the end of the paper in double line spacing, in accordance with the author submission guidelines. The review will be submitted with authorship as follows: Halley, L. and Newman, E.

Chapter 2 presents the main empirical study written up in the format of a journal article in preparation for submission to the Journal of Autism and Developmental Disabilities (see Appendix 4). This exploratory study investigates caregivers' beliefs regarding their child's Asperger's syndrome through the application of Q methodology. This study provides a detailed and comprehensive description of the methodology. The results are presented and discussed with reference to the limitations of the study, clinical implications and areas for future research. For ease of reading,

tables and figures are embedded within the text in single-line spacing; for journal submission, however, these will be at the end of the paper in accordance with the author submission guidelines. The empirical paper will be submitted with authorship as follows: Halley, L., Newman, E. and Watson, L.

The final sections of the thesis portfolio are comprised of references and appendices. The remaining document is formatted and referenced in accordance with the British Psychological Society (BPS) style guide (BPS, 2004).

Portfolio Thesis Abstract

Aims: The aims of this thesis were two-fold. First, to review the literature related to parental perceptions regarding their child's Autism Spectrum Disorder (ASD) and its effect on behavioural or emotional outcomes. Second, an empirical study aimed to explore parental beliefs about their child's Asperger's Syndrome (AS) through the application of Q methodology.

Method: A systematic review of the literature was carried out to address the first aim. The review included 7 studies; 5 quantitative and 2 mixed methodology studies. For the second aim, Q methodology was used to examine parental beliefs among a purposeful sample of 21 main caregivers of a child with AS. This methodology is based on two techniques: the q-sorting process and q-factor analysis, and aims to explore the understandings those caregivers' have of their child's AS. A set of 51 statements, representing a diverse range of opinions and perspectives on AS, was developed from a variety of sources, including bibliographic databases and online parent forums. The Q sorting process involved caregivers' arranging the statements on a quasi-normal distribution grid based upon their agreement with them.

Results: Preliminary conclusions were drawn from a synthesis of papers included in the systematic review: parental beliefs regarding their child's ASD affects their behaviour regarding treatment options and future immunisations, as well as their experience of depression, anxiety and self-efficacy. The empirical study revealed four narratives or factors from completed Q sorts: (1) AS in a positive light, (2) AS- the default diagnosis, (3) AS- what now? and (4) AS as society's problem.

Conclusions: The results from the systematic review and empirical study highlight a variety of beliefs held by parents of children with ASD. Although the implications of such beliefs were not explored in the empirical study, the results of the systematic review suggest that parental beliefs can have a significant impact on behavioural and psychological outcomes. Parental beliefs may, therefore, be an important target for clinical intervention within child and family services. It is acknowledged that further research is required to confirm and develop these findings.

Keywords: perception, belief, parent, autism spectrum disorder, Asperger's syndrome, Q methodology

Running head: *Parental perception of their child's ASD*

Chapter 1

Parental perceptions of their child's autism spectrum disorder and behavioural and psychological outcomes: A systematic review

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* The present work is written in its entirety by Lisa Halley, Trainee Clinical Psychologist, supervised by Dr Emily Newman. Dr Newman is included as a co-author for publication purposes only, in acknowledgement of her intellectual contribution. Dr Newman was not involved in the writing of this piece for the thesis.

Abstract

Parents' perceptions of their child's autism spectrum disorders (ASD) have received growing interest within the literature. This review is the first to systematically synthesise evidence about parental perceptions regarding their child's ASD in relation to behavioural and psychological outcomes. Eight databases were searched, including *PsycINFO*, *CINAHL* and *Medline*, with the keywords: 'illness perception', 'perception', 'health belief', 'belief', 'understand', 'cognition' and 'self-regulation'; cross-referenced with 'parent', 'mother', 'father', 'carer', 'family' and 'autism', 'Asperger', 'ASD', 'pervasive developmental disorder' or 'spectrum'. Seven studies met inclusion criteria. Significant relationships were found between parental beliefs regarding the cause, course and controllability of ASD, treatment choices, immunisations and parental levels of depression and anxiety. Taking account of these perceptions will enable professionals to support families in establishing realistic perceptions regarding their child's disorder. Limitations of the review are considered and recommendations for further research are provided.

Keywords: *Parental perception; beliefs; Autism Spectrum Disorder; ASD*

Parental perceptions of their child's autism spectrum disorder and behavioural and psychological outcomes: A systematic review

Autism spectrum disorders (ASDs) represent a spectrum of neurodevelopmental disorders including autism, Asperger's syndrome (AS) and pervasive developmental disorder, not otherwise specified (PDD-NOS) (Gaspar de Alba and Bodfish, 2011). ASDs are life-long conditions that impact significantly on the child and their families and are thought to affect 1% of the child population within the UK (NICE, 2011). They are characterised by impairments in social interaction and communication, as well as repetitive behaviours and restricted interests (Mercer, Creighton, Holden & Lewis, 2006). The difficulties experienced by children with ASD vary from mild to severely disabling (Hebert and Koulouglioti, 2010), making the disorders difficult to diagnose (Selkirk, Veach, Lian, Schimmenti & LeRoy, 2009) and treat (Fleischmann, 2004).

The cause of ASD remains unknown (Gaspar de Alba and Bodfish, 2011), however, epidemiological research has provided evidence supporting a genetic susceptibility (Rutter, 2005). There is an estimated 2-8% recurrence risk in families where the child with ASD has no identified co-morbid genetic condition (Herman, Henninger, Ratliff-Schaub, Pastore, Fitzgerald & McBride, 2007). In the absence of an accepted cause, course or treatment, parents can feel powerless with not knowing how best to help their child (Huws, Jones, & Ingledew, 2001) and are left to develop their own hypotheses about the cause of their child's disorder (Hebert and Koulouglioti, 2010).

Impact of ASD

Parents often experience a sense of disbelief and shock following a diagnosis of ASD (Fleischmann, 2004). High levels of psychological distress and depression have been found in mothers of children with ASD where there are increased levels of challenging behaviour and low levels of social support (Bromley, Hare, Davison & Emerson, 2004; Fletcher, Markoulakis & Bryden, 2012). The intensive care required by a child with ASD can cause considerable stress for parents (Duarte, Bordin, Yazigi & Mooney, 2005; Fletcher et al., 2012). Sanders and Morgan (1997) found that parents of children with autism experience increased stress when compared to parents of normally developing children, as well as those with Down syndrome.

Given that ASD is a complex and often misconstrued condition, parents may feel desperate and helpless when they discover that conventional medicine is of limited value (Harrington, Rosen, Garnecho & Patrick, 2006). Parents are often driven to consider treatments that are lacking in evidence, such as complementary or alternative therapies (CAM), in their desire to help their child (Gupta, 2010). Parents may blame themselves for their child's difficulties, further driving their need to try interventions that are not always recommended (Fleischmann, 2004).

Parental perceptions of ASD

A number of psychological models, including the Health Belief Model (Rosenstock, 1966) and the Theory of Reasoned Action (Fishhein and Ajzen, 1975) have attempted to explain the relationship between a person's knowledge and beliefs about illness and their behaviour. These models have been successfully applied within research on individual behaviours, e.g. treatment adherence (Broadbent, Donkin and Stroh (2011),

however, they have been criticised for their lack of consideration for emotional processes (Ogden, 1996). There is growing support for cognitive models of health behaviour, which suggests that people attempt to make sense of illness by actively constructing cognitive representations of their illness experience (Huws et al. 2001). These representations are thought to impact on their health behaviour and coping responses through a process of self-regulation (Leventhal and Diefenbach, 1996). Within this model, a person is conceptualised as an active problem solver, having to deal with both the perceived reality of their illness threat and their emotional reactions to the threat (Leventhal and Diefenbach, 1996). Leventhal proposed that illness representations are structured around five components: identity, cause, timeline, consequence and cure/control (Horne and Weinman, 2002). Later studies incorporated treatment beliefs and emotional representation into the illness perception framework (Horne and Weinman, 2002; Jessop and Rutter, 2003). Perceptions of illness can vary widely among people, despite illness severity remaining the same (Weinman and Petrie, 1997). What a person views as a life-long condition with significant consequences on their life, another may view as time-limited and minor.

Validated questionnaires have been developed that assess illness perception, e.g. the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris and Horne, 1996). These questionnaires have been used extensively within the physical health literature to demonstrate the importance of psychological theory in understanding the self-management of several chronic illnesses (e.g. Horne and Weinman, 2002; Barnes, Moss-Morris, Kaufusi, 2004). However, the illness perception framework has been applied less frequently within the mental health literature. A number of studies have utilised a modified version of the IPQ in assessing the illness perceptions of adult

patients with schizophrenia and eating disorders and their carers (e.g. Barrowclough, Hatton, Quinn, 2001; Lobban, Barrowclough, Jones, 2005; (Marcos, Weinman, Cantero, Vázquez, 2009). Research has also considered parental beliefs regarding their child's psychiatric disorder. For example, parental beliefs regarding Attention Deficit Hyperactivity Disorder (ADHD) and first-episode psychosis have been found to influence a number of health-related behaviours, such as decisions to seek treatment, as well as mediate psychological distress (Charach, Volpe, Boydell & Gearing, 2008).

Less research has focused on parental beliefs about their child's ASD and the potential outcomes of such beliefs. Hebert and Koulouglioti (2010) conducted a descriptive review of the literature exploring parental beliefs about the cause of their child's autism. They reviewed 13 papers and found that parents described a variety of beliefs, including genetic influences, immunisations, peri- and post-natal factors. A select number of these papers also reported on outcomes of parental beliefs, including decision-making regarding future health care, family planning decisions and parental mental health. Religious beliefs were associated with a reduction in parental distress. This review highlighted the variety of views held by parents about the cause of their child's autism and the potential outcomes of such beliefs. The paper did not, however, take into consideration other beliefs that parents may hold regarding their child's ASD, including the course, timeline and consequences of autism or example, and how these may affect their behaviour or psychological wellbeing. Furthermore, this previous review was not a systematic investigation of the existing literature and included studies were not critically reviewed.

Aims of review

This systematic review aims to further examine parental beliefs about their child's ASD and the effect of their beliefs on parental behaviour and psychological well-being.

Methodology

Search strategy

A systematic search strategy was adopted with the aim of minimising biases in study selection. Searches were conducted using electronic bibliographic databases (*PsycINFO, Embase, CINAHL, Medline, AMED, ERIC, Cochrane Library, and Web of Knowledge*), reference lists from key articles and a manual search of the British Journal of Clinical Psychology, the Journal of Autism & Developmental Disabilities, Autism and the Journal of Intellectual & Developmental Disabilities. Searches were carried out in July 2013 and were limited to studies published in the English language between January 1992 and December 2012 inclusive. Search terms are presented in Table 1.1. All titles were screened for variables of interest. Of those retrieved, abstracts and full articles were screened according to pre-determined inclusion and exclusion criteria. A final sample of 7 papers was used in the review. Where two studies using the same data set were identified, the study most relevant to the area was included. If both studies were relevant, they were both included but treated as a single study to reduce duplication bias (Centre for Reviews and Dissemination; CRD, 2008).

Table 1.1. Key search terms used to search electronic databases

<i>Keywords</i>				
<i>Illness perception</i>		<i>Parent</i>		<i>Autis*m</i>
<i>or percept*ion</i>	<i>and**</i>	<i>or mother</i>	<i>and**</i>	<i>or Asperger</i>
<i>or health belief</i>		<i>or father</i>		<i>or ASD</i>
<i>or belief</i>		<i>or carer</i>		<i>or pervasive</i>
<i>or underst*and</i>		<i>or family</i>		<i>developmental disorder</i>
<i>or cognit*ion</i>				<i>or spectrum</i>
<i>or self regulation</i>				

Inclusion/exclusion criteria

Studies were included if they met the following criteria:

1. Included parents of children with a diagnosis of ASD. In order to establish a representation of parental views across the life span, studies including children and adult children (>18 years) were included.
2. Included a measure of parental beliefs as the main variable of interest or, for qualitative studies, the primary focus was on parental beliefs about their child's ASD.
3. Reported data from, at least, one measure of behavioural or psychological outcome.
4. Published in a peer-reviewed journal.

Studies were excluded based on the following criteria:

1. Previous literature reviews, systematic reviews, meta-analyses.
2. Unpublished dissertations/abstracts, conference abstracts, book chapters/reviews.
3. Single case reports and clinical case series.
4. Parental identification of ASD

Quality assessment

Quality assessment tools were developed for the purpose of the review following consultation with guidelines on methodological quality for non-RCT research studies, including STROBE (von Elm, Altman, Egger, Pocock, Gøtzsche & Vandembroucke, 2007) and SIGN Methodology Checklist (SIGN, 2004). Studies that utilised mixed methodology were subject to additional criteria based on a tool proposed by the British National “Critical Appraisal Skills Programme” Collaboration (CASP, 2010) to ensure relevant aspects of quality were being measured (see Appendix 2 and 3).

Both tools utilised the same scoring method; e.g. one mark was given if criteria were clearly defined and no mark was given if the criteria were not mentioned or were not clearly defined. Each study was scored out of a possible 22 points for quantitative studies or 29 points for mixed method studies and percentages were calculated to determine the strength of quality. Studies were arbitrarily categorised as high quality >70%, moderate quality 50-70% or low quality <50%. Whilst it is recognised that the rating scale does not allow for direct comparative measurement across studies, it illustrates the study’s relative methodological strengths and weaknesses. Included studies were assessed for methodological quality by the first and second authors. Discrepancies in ratings were resolved through discussion.

Data extraction and synthesis

Given the methodological diversity of included studies, the formal pooling of results was considered inappropriate. A narrative synthesis approach was carried out to collate and summarise the findings of included studies (CRD, 2008), taking into

consideration the general characteristics and quality assessment of the studies. Data extracted from studies included: study design, sample size and characteristics, measures of perception and other outcomes, method of analysis and main findings.

Results

Study selection

Combined database searches returned 2711 studies: 1511 were initially excluded on the basis of duplication and title. Abstract screening excluded 960 studies. The remaining 240 studies were retrieved in full and screened for relevance. A further 210 studies were excluded as they did not measure parental perceptions. Twenty-one studies did not include an outcome measure. Two papers were excluded as they reported parental identification of ASD. One additional study was identified from a reference search and then subsequently excluded, as the results were not specific to ASD. The search and selection process is depicted in Figure 1.1. A final sample of 7 studies met the inclusion criteria and was reviewed in full. Five were quantitative in design and two were of mixed methodology. Two relevant studies used the same data set, thus, their results were combined and viewed as a single study, leaving 6 studies for review.

Study characteristics

A description of methodological characteristics, main findings and quality assessment of included studies is presented in Table 1.2 in alphabetical order.

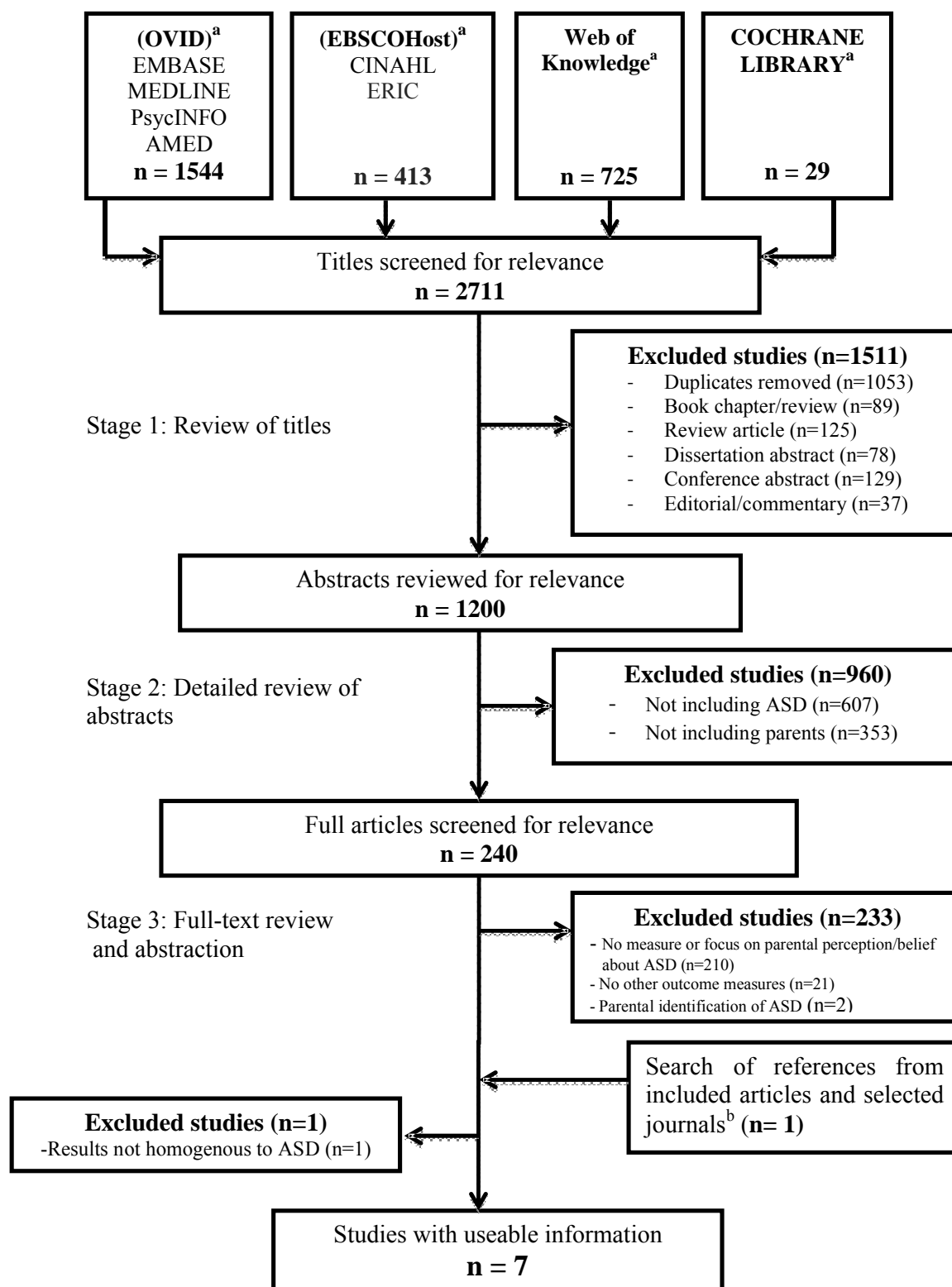


Fig 1.1 Schematic representation of search

^a Limits of search included articles published between January 1992 and December 2012 (inclusive) and English language.

^b Full electronic journal searches of: British Journal of Clinical Psychology, Journal of Autism & Developmental Disabilities, Autism and Journal of Intellectual & Developmental Disabilities.

Table 1.2. Methodological characteristics and main findings of included studies

Author/ Year	Study design	Sample/diagnosis	ASD perception constructs	Psychological or behavioural outcome	Method of Analysis	Main findings
Al Anbar et al. (2010) ^a & Dardennes et al. (2011) ^a	Cross- sectional	N=89; Mothers n=65; Fathers n=21; other n=3; Age range = 40.9-45.4 years Child diagnosis: Autism n=52; AS n=14; PDD-NOS n=19; NS n=4; boys n=67; Age range =11.04-15.19 years	<i>Revised Illness Perception Questionnaire (IPQ-R;</i> Moss-Morris et al. 2002) modified for autism; Causes of autism as measured by the <i>Lay Beliefs about Autism Questionnaire</i> (LBA-Q; Furnham & Buck, 2003)	<i>Ad hoc</i> questionnaire measuring treatments used and information seeking methods	Exploratory multiple regressions (stepwise)	Brain abnormalities were the most highly rated cause of ASD among parents Perception of seriousness of ASD and genetic cause was associated with use of educative methods training programs. Higher beliefs in illness during pregnancy were associated with increased use of medication. An attribution of food allergy was associated with special diets and vitamins. Perceiving brain abnormalities as the cause of ASD was associated with a decreased use of vitamins. Unpredictable course of ASD was associated with drug use. Higher sense of personal control and beliefs in the etiological role of food allergy was associated with reduced drug use.
Cappe et al. (2011)	Cross- sectional	N=160; Mothers n=113; Fathers n=47; age range= 29-70 years Child diagnosis: Autism n=87; PDD-NOS n=10; AS n=21; boys n=94; girls n=24	<i>Adapted Cancer Locus of Control Scale (CLCS;</i> Cousson-G��lie et al. 2005)	<i>Appraisal of Life Events Scale</i> (ALES; Ferguson et al. 1999); <i>QSSP</i> (Koleck, 2000); <i>Ways of Coping Checklist (WCC-R;</i> Cousson et al. 1993); <i>Ad hoc</i> Quality of Life scale	Bivariate correlations; principle component analysis; and multiple regression analyses	Parents who perceive their experience of having a child with PDD as a threat and a loss have a lower quality of life and poorer adaptation to their child's disorder. Parents who perceived their child's PDD as a challenge had a better relationship with their child, greater self-fulfillment, and

Table 1.2. Methodological characteristics and main findings of included studies (*Continued*)

Author/ Year	Study design	Sample/diagnosis	ASD perception constructs	Psychological or behavioural outcome	Method of Analysis	Main findings
Cappe et al. (2011) cont.		Age range= >6 - >18 years				employed a range of coping strategies.
Dale et al. (2006)	Mixed methods	Mothers N= 16; Age range = 28-44 years Child diagnosis: Autism n=; 11; AS n=5; boys n=11; girls n=5; Age range= 3-9 years	<i>Semi-structured interview</i> regarding the cause, stability and controllability of ASD	<i>Beck Depression Inventory</i> (Beck et al. 1996); <i>Parenting stress index</i> (Abdin, 1995); <i>Child Expectation Scale</i> (Dunst & Trivette, 1986).	Bivariate correlations; content analysis	Most mothers did not ascribe their child's AS to a particular cause and felt uncertain about prognosis. Mothers who felt they held too much responsibility were more stressed than those who did not. Mothers who reported higher levels of personal control reported higher levels of depressed affect. Five mothers believed MMR vaccination caused their child's ASD, affecting their decisions regarding future vaccinations. Most mothers were more focused on their child's future than thinking about a cause.
Harrington et al. (2006)	Cross sectional	N=77b Child diagnosis: autism n=37; PDD-NOS n=29; AS n= 8; ^d Rett syndrome n= 3; boys n= 60; girls n=17; age range = 2-19 years	<i>Ad hoc survey</i> examining parental beliefs about cause of ASD	<i>Ad hoc</i> checklist of treatments used by parents	Descriptive analysis	Fifty-four percent of parents rated immunisations as main cause of ASD, followed by genetic predisposition (53%) and environmental exposure (38%). Fourteen percent of parents believed there was no specific cause. One in five parents indicated they would withhold future immunisations.

Table 1.2 Methodological characteristics and main findings of included studies (*continued*)

Author/ Year	Study design	Sample/diagnosis	ASD perception constructs	Psychological or behavioural outcome	Method of Analysis	Main findings
Harrington et al. (2006) cont.						Ninety-two percent of parents utilised CAM therapies.
Pakenham et al. (2004)	Mixed methods	N= 59; Mothers n=47; Fathers n=12; Age range= 28-51 years Child diagnosis. AS n=59; boys n=50; girls n=9; Age range = 10-12 years	<i>Open ended question</i> on finding benefits and making sense of having a child with AS	<i>Eyberg Child Behaviour Inventory (ECBI</i> ; Eyberg & Pincus, 1999); <i>Social readjustment rating scale (SRRS</i> ; Holmes & Rahe, 1967); <i>Brief social support questionnaire</i> (Siebert et al. 1987); <i>parental stress in management of Asperger's syndrome Scale</i> (Sofronoff, 2002); <i>parental self-efficacy scale</i> (Sofronoff & Farbotko, 2002); <i>COPE</i> (Carver et al. 1989); <i>Depression Anxiety Scale (DASS21</i> ; Lovibond & Lovibond, 1995); <i>Social Adjustment Self report Questionnaire</i> (Weissman, 1986); <i>Global rating of subjective health status</i>	Content analysis; bivariate correlations	Content analysis of open ended questions revealed 12 sense making and 8 benefit finding categories, of which the most frequently reported was developing a greater understanding of AS and positive personality changes. Higher levels of reported benefit finding and sense making were related to greater perceived stressful life events. Benefit finding was associated with seeking instrumental support whilst sense making was related to seeking emotional support coping. Higher levels of meaning making were related to greater reliance on problem- focused and emotional approach coping strategies.
Samios et al. (2009)	Cross sectional and longitudinal	N=218c; Mothers n=130; Fathers n=87; Age 27-63 years Child diagnosis. AS n= 198; boys n=168;	<i>SMS-PCAS</i> -61 item scale consisting of statements that parents of a child with AS have used to make sense of their child having AS	<i>Sense of Coherence Scale (SOC-M</i> ; Antonovsky, 1987); <i>Depression, Anxiety and Stress Scale (DASS-21</i> ; Lovibond, 1995).	Bivariate correlations; hierarchical regression analysis	Reframing AS as a difference rather than a disorder was related to better adjustment, whereas explaining AS as luck or fate and maintaining a spiritual perceptive was related to poorer adjustment.

Table 1.2 Methodological characteristics and main findings of included studies (*continued*)

Author/ Year	Study design	Sample/diagnosis	ASD perception constructs	Psychological or behavioural outcome	Method of Analysis	Main findings
Samios et al. (2009) cont.		girls n=30; Age 5-18 years				Adjustment was stable across a 12 month period, suggesting that sense making is more important for adjustment in the first months following diagnosis.

Full study references are marked with an * in the reference section.

^aDardennes et al. 's (2011) study is based on a secondary analysis of data collected in Al Anbar et al.'s (2010) study. The results of both studies were therefore combined to form a single study.

^b This study did not provide participant demographic information

^c One participant did not provide demographic information

^d Parents of children with Rett syndrome were excluded from analysis in this study due to the small sample size.

Abbreviations: ASD: Autistic Spectrum Disorder; PDD-NOS: Pervasive Developmental Disorder-Not Otherwise Specified; NS: Not specified; CAM: complementary or alternative therapies.

Participants

A total of 619 participants were recruited across studies. Sixty-eight per cent of the total sample was comprised of mothers, 31% fathers, and 1% 'unknown'. Parent gender was not reported in one study (Harrington et al., 2006), therefore, is not included as part of this percentage. The age range in the five studies that reported age was 27 to 70 years. Where ethnicity was reported, over 80% of participants were Caucasian/White. Four studies included children with autism (64%), 16 (28%) and PDD-NOS (20%). Two studies recruited only parents of children with AS. Child age ranged between 2 and >18 years. Two studies included adult children (>18 years). Four hundred and fifty children were male and 107 were female, giving a similar estimated 4:1 gender ratio to the epidemiological prevalence of ASD (Fletcher et al., 2012). Only one study reported the intellectual ability of the children with ASD and found them to be within the moderate-low or low ability ranges (Dale, Jahoda & Knott, 2006).

Parents were recruited from specialist multi-disciplinary clinical teams and psychiatric services (Cappe, Wolff, Bobet & Adrien, 2011; Dale et al. 2006; Samios, Pakenham & Sofronoff, 2009), private paediatric services (Harrington et al. 2006); a university intervention program (Pakenham, Sofronoff & Samios, 2004; Samios et al. 2009), autism-based societies (Al Anbar, Dardennes, Prado-Netto, Kaye & Contejean, 2010; Dardennes, Al Anbar, Prado-Netto, Kaye, Contejean & Al Anbar, 2011), parent associations and community groups (Al Anbar et al. 2010 & Dardennes et al. 2011; Cappe et al. 2011). Studies were conducted in Australia, France, the United Kingdom and the United States of America.

Design

Five papers adopted a cross-sectional design and one paper used cross sectional and longitudinal data (Samios et al. 2009). Correlational analysis was used in 4 studies and one reported descriptive statistics only. Content analysis was used in both mixed method studies.

Parental perceptions

Different measures were used to examine parental beliefs about their child's ASD. Al Anbar et al. (2010) and Dardennes et al. (2011) modified a version of the *Revised Illness Perception Questionnaire (IPQ-R)*; Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002) and extracted causal beliefs from the *Lay-Beliefs about Autism Questionnaire (CBA)*. Cappe et al. (2011) adapted the *Cancer Locus of Control scale* to assess perceptions of control concerning their child's ASD and religious beliefs. Samios et al. (2009) developed the *Sense Making Scale for Parents of Children with AS (SMS-PCAS)* based on qualitative data from a previous study. Mixed methods studies measured parental beliefs using an in-depth semi-structured interview (Dale et al. 2006) and open-ended questions (Pakenham et al. 2004). One paper designed an *ad hoc* questionnaire to obtain information on beliefs about the cause of the child's disorder (Harrington et al. 2006).

Behavioural and psychological outcomes

Psychological wellbeing was examined through parenting stress (Cappe et al. 2011; Dale et al. 2006; Pakenham et al. 2004), depression (Dale et al. 2006), quality of life (Cappe et al. 2011), self-efficacy (Dale et al. 2006; Pakenham et al. 2004), coping (Cappe et al. 2011; Pakenham et al. 2004), distress (Pakenham et al. 2004; Samios et

al. 2009), social functioning (Pakenham et al. 2004), positive affect (Samios et al. 2009), life satisfaction (Samios et al. 2009) and general health status (Pakenham et al. 2004; Samios et al. 2009). Two studies examined the effect of beliefs on treatment choices (Al Anbar et al. 2010 & Dardennes et al. 2011; Harrington et al. 2006) and two examined beliefs about vaccinations (Dale et al. 2006; Harrington et al. 2006). One study measured the impact of beliefs on adjustment outcomes at 12 months follow up (Samios et al. 2009).

Quality assessment

Table 1.3 provides a summary of the methodological strengths of the reviewed studies. Inter-rater reliability of the quality assessment tools was determined using the Kappa statistic. On the basis of scores from a random sample of 4 of the 6 studies, the inter-rater reliability quotient was high ($Kappa = 0.75$; $p < 0.05$) (Cohen 1988), suggesting good overall agreement between raters.

Quality ratings of included quantitative studies ranged from 45% to 82%: suggesting one low (Harrington et al. 2006), one moderate (Al Anbar et al. 2010 & Dardennes et al. 2011) and two high quality (Cappe et al. 2011; Samios et al. 2009) studies. Both mixed methodology studies were considered to be high quality (Dale et al. 2006; Pakenham et al. 2004), with ratings ranging from 72-83%.

Table 1.3. Methodological assessment of the four qualitative studies and two mixed method studies included in the review

Quality Criteria	Included Studies					
	Al Anbar et al. (2010) & Dardennes et al. (2011)	Cappe et al. (2011)	Harrington et al. (2006)	Samios et al. (2009)	Dale et al. (2006) ^a	Pakenham et al. (2004) ^a
Does title or abstract include adequate description of experimental design?	Yes	Yes	Yes	Yes	Yes	Yes
Does abstract include relevant diagnoses of participant group(s)?	Yes	Yes	Yes	Yes	Yes	Yes
Does abstract provide an informative and balanced summary of what was done and what was found?	Yes	Yes	Yes	Yes	No	Yes
Does the introduction clearly outline the scientific background information and link this to a rationale for the study?	Yes	Yes	No	Yes	Yes	Yes
Are the hypotheses/aims/objectives of the study clearly described?	Yes	Yes	No	Yes	Yes	Yes
Is the study design appropriate to test the hypotheses?	Yes	Yes	Yes	Yes	Yes	Yes
Were settings/locations of data collection stated?	Yes	Yes	Yes	Yes	Yes	Yes
Are the eligibility criteria clearly specified?	No	Yes	No	Yes	Yes	Yes
Is the population, and how it was identified/recruited clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes

Table 1.3. Methodological assessment of the four qualitative studies and two mixed method studies included in the review (*continued*)

	Al Anbar et al. (2010) & Dardennes et al. (2011)	Cappe et al. (2011)	Harrington et al. (2006)	Samios et al. (2009)	Dale et al. (2006) ^a	Pakenham et al. (2004) ^a
Did recruitment avoid convenience sample (e.g. clinic/service/other research project)/ bias wherever possible?	No	No	No	No	No	No
Is there an explanation for how study size was arrived at (e.g. power calculations)?	No	No	No	No	Yes	No
Were measurement tools valid, reliable and sensitive to change?	No	Yes	No	Yes	No	Yes
Does the study report the number of participants at each stage of the study (e.g. potentially eligible, confirmed eligible, included in study, completing follow up, analysed)?	No	No	Yes	Yes	No	Yes
Does the study provide characteristics of study participants?	Yes	Yes	Yes	Yes	Yes	Yes
Does the study indicate number of participants with missing data for each variable of interest?	No	No	No	No	No	No
Is there adequate reporting of descriptive statistics (i.e. means, standard deviations)?	Yes	No	Yes	No	No	Yes
Were the statistical analyses used to assess the main outcomes appropriate and clearly related to the study aims, questions and hypotheses?	Yes	Yes	No	Yes	Yes	Yes

Table 1.3. Methodological assessment of the four qualitative studies and two mixed method studies included in the review (*continued*)

	Al Anbar et al. (2010) & Dardenne et al. (2011)	Cappe et al. (2011)	Harrington et al. (2006)	Samios et al. (2009)	Dale et al. (2006) ^a	Pakenham et al. (2004) ^a
Does the analysis control for the potential impact of other variables?	Yes	Yes	No	Yes	No	No
Does the study summarise key results with reference to study aims and objectives?	Yes	Yes	No	Yes	Yes	Yes
Are the limitations of the study clearly expressed, taking into account sources of potential bias or imprecision?	No	Yes	No	Yes	Yes	Yes
Does the study address the generalisability (external validity) of the results?	Yes	Yes	Yes	Yes	Yes	Yes
Are recommendations for clinical practice or future research discussed in relation to the findings?	Yes	Yes	No	Yes	Yes	Yes
Is qualitative methodology appropriate?					Yes	Yes
Were the interview questions predefined?					Yes	Yes
Was interview data transcribed verbatim?					Yes	Yes
Was saturation mentioned?					No	No
Was there a description of how the themes were derived from the data?					Yes	Yes

Table 1.3. Methodological assessment of the four qualitative studies and two mixed method studies included in the review (*continued*)

	Al Anbar et al. (2010) & Dardennes et al. (2011)	Cappe et al. (2011)	Harrington et al. (2006)	Samios et al. (2009)	Dale et al. (2006) ^a	Pakenham et al. (2004) ^a
Were the findings analysed by more than one assessor?					Yes	Yes
Were quotes presented in the report?					Yes	Yes
Total score (%)	15 (68%)	17 (77%)	10 (45%)	18 (82%)	21 (72%)	24 (83%)

^a These studies used mixed quantitative and qualitative design

Main findings

Parental perceptions regarding their child's ASD are presented, followed by a review of the relationship between beliefs and parental behaviour and psychological outcomes.

Parental beliefs regarding their child's ASD

Causes of ASD

Three studies examined beliefs about the cause of their child's ASD (Al Anbar et al. 2010 & Dardennes et al. 2011; Dale et al. 2006; Harrington et al. 2006).. All studies enabled participants to endorse multiple causes for their child's ASD, thus, percentages often total >100%. Genetic influences were amongst the most frequently cited causes. In Harrington et al.'s (2006) study, parents were asked to choose from a list of commonly cited causes of ASD and over half cited genetic influences as a potential cause (53%). Using causal beliefs from the Lay-Beliefs about Autism Questionnaire, Dardennes et al. (2011) found that 77% of parents reported ASD as being due to genetic factors. In contrast, Dale et al. (2006) found that only two out of 16 parents attributed cause to hereditary during a semi-structured interview.

Immunisations and vaccinations were also perceived as a risk factor in two studies and were the most commonly cited cause of ASD in Harrington et al.'s (2006) study (54%). Five out of 16 parents in Dale et al.'s (2006) study attributed ASD to the MMR vaccination. In contrast, vaccines were rarely cited as a cause in Dardennes et al. (2011) study with only 4% of parents freely citing it as a cause.

One study reported prenatal maternal factors as possible causes of ASD (Dardennes et al. 2011). In this study, 42% of parents, at least slightly agreed that pregnancy complications contributed to their child's ASD. Parents reported alcohol, smoking and advanced parental ageing as potential causes, although to a lesser extent, in Al Anbar et al.'s (2010) study (exact numbers not reported). Premature birth was cited as a possible cause by 4% of parents (Harrington et al. 2006) as well as perinatal causes, such as brain abnormalities (90% Dardennes et al. 2011), immune dysfunction (2.9% Dardennes et al. 2011) and early childhood illness or injury (8%; Harrington et al. 2006). Beliefs regarding parenting failure were rejected in Dardennes et al.'s (2011) study by 89.7% of parents.

A number of parents attributed their child's ASD to be the result of random chance, bad luck or fate (Al Anbar et al. 2010) (exact numbers not reported). Food allergies were also considered by 27% of parents to cause ASD in one study (Dardennes et al. 2011).

A large proportion of parents (86%) in the Harrington et al (2006) study believed there was a specific cause of ASD. In contrast, only 31% of parents in Dale et al.'s (2006) study attributed their child's ASD to a particular cause. Pakenham et al. (2004) reported that, for some parents, their priority was focusing on their child's future rather than searching for explanations for what might have caused their child's ASD.

Course of ASD

Two studies examined parental beliefs regarding the course of their child's ASD. Two out of 16 mothers in Dale et al.'s (2006) study viewed ASD as a life-long condition

and avoided thinking about the future. In contrast, five mothers perceived ASD as unstable and believed their child would overcome their difficulties, by “out-growing” it or through advances in research and treatment. Two mothers believed their child would become more accepted within society and that ASD would be viewed as a personality type rather than a disorder. Overall, the parents in Al Anbar et al.’s (2010) study viewed their child’s ASD to be a chronic condition ($M=25.1$, $SD=3.6$) that is cyclical in nature ($M=12.6$, $SD= 3.2$).

Controllability

Two studies considered parental beliefs regarding controllability of ASD. Forty three per cent of mothers felt personally responsible for helping their child in Dale et al.’s (2006) study. In contrast, 25% of mothers felt that “experts” held the control. Parents reported a general belief of having personal control in Al Anbar et al.’s (2010) study ($M=21.1$, $SD=4.0$) as well as a moderate belief that treatment can control their child’s ASD (17.6 , $SD=3.3$).

Re-framing

Two studies considered parental perception in the broader sense of sense making and benefit finding. Seven per cent of parents in Pakenham et al.’s (2004) study reported making sense of their child’s ASD by reframing ASD as a ‘difference’ rather than a disorder. A further 29% of parents also reported changing their perspective on life and expectations of their child. Using principal components factor analysis, Samios et al. (2009) identified factors by which parents of children with AS use to make sense of their child’s disorder which included changing their view of the disorder, reframing AS as a difference and identifying themselves with their child.

Outcomes of parental beliefs about their child's ASD

Treatment choices

Two studies examined treatment choices. Harrington et al. (2006) found dietary changes and the use of supplements were the most common therapies used by parents. Over half of parents utilised a gluten-free diet (52.7%) and increased essential fatty acids in their child's diet (51.4%). Half of parents (50%) reported using sensory integration and 40.5% utilised antifungal treatment. Educative methods were the most commonly cited treatment methods (68.5%) in Al Anbar et al.'s (2010) study, followed by behaviour therapy (40.4%), metabolic treatments (30.3%), drugs (27%), vitamin supplements (22.5%) and special diets (19.1%).

Dardennes et al. (2011) found five causal beliefs to be statistically associated with treatment choices: parents who considered early traumatic experiences to have caused ASD were less likely to use behaviour therapy, believing that food allergies or a chemical imbalance caused ASD was associated with increased use of special diets and vitamins but a decrease in use of drugs, and belief in brain abnormalities was associated with decreased use of vitamins. Al Anbar et al. (2010) found that parents who viewed ASD as a serious disorder were more likely to use educational methods or social skills therapy. Viewing ASD as unpredictable was associated with increased drug use and parents with highly perceived levels of personal control were less likely to use nutritional or pharmacological treatments.

Immunisation status

Two studies reported on parental beliefs and decisions regarding immunisations. Thirty one per cent of mothers in Dale et al.'s (2006) study who believed that the

MMR vaccination played a role in the development of ASD took protective action against further immunisations of their child and subsequent children. A greater proportion of parents (40.5%) in Harrington et al.'s (2006) study, who suspected a specific cause of ASD, also reported delaying or withholding vaccinations, however, relationships between specific beliefs and decisions regarding vaccinations were not reported.

Parental psychological wellbeing

Four studies measured psychological wellbeing in relation to parental beliefs. Dale et al. (2006) found that mothers who perceived greater control over their child's ASD reported higher levels of depressed affect, as measured by the Beck Depression Inventory (Beck et al. 1996). Common symptoms reported included irritability, guilt, sadness and self-criticism. This finding rejected the authors' hypothesis that parents would report high levels of depressed affect in relation to perceived poor control. The qualitative data supporting this finding suggests that these parents felt over-whelmed, burdened and unable to cope with the perceived responsibility in helping their child and this had a negative impact on their mood. In contrast, Cappe et al.'s (2011) study found that parents who perceived poor control over their child's ASD also reported increased feelings of guilt. Guilt in this study was measured as parents' perceived responsibility in the cause of their child's ASD; thus, those parents who believed they had contributed to the cause of their child's ASD also felt they had poor control over their child's ASD.

Samios et al. (2009) examined the association between perceptions regarding AS and positive and negative indicators of adjustment. Parents who considered their child's

disorder to be as a result of luck or fate reported increased levels of depression and anxiety. Similarly, attributing their child's AS to God was associated with increased anxiety. In contrast, perceiving AS as a "difference" rather than disorder was associated with lower levels of depression and anxiety. Parental perceptions regarding AS did not predict adjustment at 12 months follow up (Samios et al. 2009).

Greater parental self-efficacy was associated with parental sense making and benefit finding variables in Pakenham et al.'s (2004) study. In contrast, Dale et al. (2006) found no association between mothers' beliefs about the cause of their child's ASD and their perceived parental competence. Perceiving their experience of ASD as threatening was the strongest predictor of poor quality of life in Cappe et al.'s (2011) study. In contrast, perceiving their experience as a challenge was the strongest predictor of self-fulfillment.

Pakenham et al. (2004) found no relationship between sense making and benefit finding variables and self-reported stress relating to raising a child with ASD. Holding the belief that there may be some eventual benefits in having a child with AS was, however, positively associated with 'pile up of demands', as measured by distress experienced in relation to stressful life events.

Coping

Two studies considered the impact of parental beliefs on coping. Cappe et al. (2011) found that parents who perceived their experiences as threatening or as a loss utilised more emotion-focused coping strategies. In contrast, those who viewed their experience of having a child with ASD as a challenge were more likely to utilise

problem-solving strategies to cope with their child's difficulties. Pakenham et al. (2004) also found strong associations between parental perceptions and various problem and emotional-focused coping strategies, including: planning and active coping, positively re-interpreting their situation, turning to religion, accepting their situation and seeking social support for instrumental reasons.

Discussion

This review highlights the variability in beliefs held by parents of children with ASD. Although it is recognised that the results of included studies could not be compared directly due to variation in methodology, general trends of parental beliefs were identified, if only reflecting the results of those studies included in the review. Consistent with current theories and clinical views, the majority of these studies identified genetic influences as a key parental perception regarding the cause of ASD and the impact of environmental triggers on genetic susceptibility; thus, concurring with recent epidemiological findings (Newschaffer, Croen, Daniels, Giarelli, Grether, Levy, et al., 2007). However, there remained a considerable number of studies reporting variability in parental beliefs regarding ASD, highlighting that some parents continue to attribute ASD to childhood immunisations; despite the consistent lack of evidence to support this (Miller, 2003). This may be a reflection of the on going debate and media attention around childhood vaccinations (Selkirk et al. 2009). Furthermore, these beliefs were found to negatively impact on decisions regarding future immunisations in one study. Although the relationship between specific beliefs regarding the cause of ASD and decisions regarding future vaccinations was not reported in the other study, a positive relationship is assumed. These findings highlight the importance of discussing parental beliefs following their child's

diagnosis of ASD. Given the plethora of causes reported in this review, it is reasonable to suggest that identifying a cause for their child's ASD is of significant importance for parents. It is proposed that it may assist with the adjustment process and help reduce feelings of guilt (Dale et al. 2006).

The studies included in the current review highlight the variety of treatments utilised by parents and the impact of perceptions on treatment choices. The difference in treatments utilised between studies is likely to reflect their different objectives. For example, Harrington et al. (2006) focused on parental views and utilisation of CAM therapies in particular and did not provide options for educative or behavioural treatments. Cultural differences may also have affected these results. Al Anbar et al. (2010) and Dardennes et al. (2011) carried out their studies in France where educational interventions are one of the most widely used methods, therefore, it is not surprising that these interventions were the most commonly endorsed by parents in this study. The association between understandings of ASD and treatments utilised by parents, as shown in this review, highlights the need for professionals to inquire about parental beliefs. This may help identify those beliefs that are unhelpful or may uncover information needed to reduce potentially unhelpful practices.

It is widely known that raising a child with ASD can be a stressful experience (Sanders and Morgan, 1997), which may result in increased levels of parental depression and anxiety. Although a causal relationship cannot be confirmed from the results of this review, from the associations found, it would be appropriate to suggest that helping parents to modify how they perceive their child's ASD and re-appraise their situation may help to improve their psychological well being.

Methodological consideration of included studies

Measures of Parental Perception

Given that there are a limited number of existing measures designed to measure parental beliefs about their child's ASD, a variety of measures were used in the current review. Several studies developed or adapted well-known and psychometrically sound measures for the purpose of their research (e.g. Al Anbar et al., 2010; Cappe et al., 2011). One study utilised an *ad hoc* questionnaires and one study designed a questionnaire based on a previous qualitative study. Although it could be argued that all measures are appropriate and useful for the purposes of the individual study, the reliability or validity of such measures were not reported for use with this population.

A focus on causal beliefs was a dominant theme throughout the studies in this review. As demonstrated by Pakenham et al. (2004) and Samios et al. (2009), how parents make sense of their child's disorder is not limited to understanding causal factors. One study used semi-structured interviews to examine parental perceptions regarding their child's ASD (Dale et al. 2006). This study, by design, focused on parental perceptions in three areas: cause, stability and controllability. Although considered a useful methodology in that it captures the subjective nature of a person's viewpoint, the study design limits the generalisation of results to the wider population.

Quality of reported data

The quality of studies varied, although all papers were considered to be adequately designed for inclusion in the review.

Quantitative studies

No quantitative studies met all quality criteria. A significant problem was potential recruitment bias as all studies utilised a convenience sample and only two studies reported clear eligibility criteria. No studies reported on missing data for all variables. It is not certain whether any of the included studies achieved sufficient power, as power calculations were not reported. Reliability and validity of measures was not reported in two studies. Three out of the four studies controlled for other variables in their analysis. Given the methodological limitations of these studies, their results should be interpreted with caution.

Mixed methodology studies

No qualitative studies met all quality criteria. Saturation of data was not mentioned in either study; however, both studies validated their findings with another researcher. In relation to quantitative criteria, similar to those above, convenience sampling was used in both studies. Neither study controlled for other variables in their quantitative analysis, potentially confounding their results, and power was reported in only one study. Given the limited generalisability of these results, they too should be interpreted with caution.

Considerations and limitations of systematic review

Only 7 studies met inclusion criteria for review. The majority of studies recruited predominantly White mothers, some of whom attended parent associations. This is likely to be a pro-active and highly resourceful group. A number of participants were also recruited from psychiatric or paediatric services, therefore, it is likely that they will have received a significant amount of reliable information and advice regarding

ASD. Only 2 studies considered the differences between respondents and non-respondents. It is possible, therefore, that the results of this review may represent biased sampling.

Although the review adopted broad inclusion criteria to investigate a varied view of parental perceptions across the age range, only two studies included children over the age of 18 years. For the reasons provided, the generalisation of results to other population groups is limited. No studies utilised a control group, therefore it is not possible to confirm that the results reported are representative of parents of children with ASD only, or whether parents of children with other disabilities report similar findings, or indeed if the views differ from the general population. It is also of note that the majority of studies reported on the combined perceptions of parents of children across the autism spectrum. It is probable that the beliefs of parents of children with autism may vary significantly from those with AS or PDD-NOS given the variability in expression of the different conditions. Furthermore, children with autism are at increased risk of a co-morbid learning disability, thus, are likely to present with a range of different difficulties or limitations. Only one study reported the ability range of the children (Dale et al. 2006).

It is recognised that no attempt was made to reduce publication bias in this review. Published articles are readily available for evaluation and time constraints prevented unpublished material and dissertations from being accessed. Inclusion of this “grey literature” may have broadened the perspective and enabled comparisons to be made. The inclusion of studies with heterogeneous methods for assessing parental perceptions prevented a meta-analysis from being carried out, thus, opening the

review to subjective bias (CRD, 2008). One study that met inclusion criteria was based on a secondary analysis of data collected in another included study, however, in an attempt to prevent an overestimation of the results, the primary author combined the results of both studies and reviewed them as a single study. Finally, the majority of studies included in the review employed a cross-sectional design. Although a number of significant relationships were observed in the review, the causality cannot be confirmed.

Implications for clinical practice

This review highlights the importance of health professionals taking time to understand parental beliefs about their child's ASD. Parents' beliefs may differ from the medical professional's, affecting the development of a trusting and collaborative relationship (Harrington et al. 2006). It may help professionals guide parents towards effective treatments (Charach et al. 2008) and prevent children from receiving potentially harmful practices, such as dietary restrictions that may affect nutrient levels, or the withholding of immunisations, which may expose children to greater health risks. Furthermore, professionals will be in a better position to help parents develop realistic expectations and work towards achievable goals (Hebert and Koulouglioti, 2010).

Identification of parental beliefs about their child's ASD may also be invaluable in informing suitable interventions that focus on modifying unhelpful beliefs, with the aim of reducing family distress, enhancing well-being, and helping parents to make informed choices regarding other forms of treatment. Interventions that focus on cognitive re-structuring may enable parents to re-appraise their situation, help them to

re-frame their child's behaviours and focus on their child's strengths (Pakenham et al. 2004).

Future directions

Parental beliefs regarding their child's ASD remain an under-researched area. The majority of studies focus on parental perceptions about the cause of their child's ASD, however, as a number of studies have highlighted, making sense of their child's disorder is not limited to causal perceptions (e.g. Pakenham et al. 2004; Samios et al. 2009). Parents may draw upon religious beliefs, as well as embrace personal changes and re-affirm their values when making sense of their child's disorder. It is important that future research considers parental perceptions in the wider sense, taking into consideration their beliefs about the cause, course and controllability of ASD, as well as any changes in personal and family values, personality, cultural and religious beliefs. It is also important that further research examines the positive perceptions that parents may hold regarding their child's ASD.

Future research should consider more robust ways of measuring perceptions that can be administered to a large population. The majority of measures in this review were developed or adapted for use with the ASD population. Replication of studies is required to test the reliability and validity of such measures with this population. Q sort methodology is considered a useful way of examining perspectives (Watts & Stenner, 2012) and may be a useful avenue for future research. Longitudinal data is also required to ascertain the stability of beliefs over time (Al Anbar et al. 2010). Without this information, it is difficult to make stronger inferences about the impact of parental beliefs on different outcomes over time (Cappe et al. 2011).

Conclusion

This review sought to investigate the relationship between parental perceptions about their child's ASD and a range of behavioural and psychological outcomes. Results suggested that parental perceptions were significantly associated with treatment and vaccination choices, depression, stress, and coping styles. There is, however, a continuing need to explore parental perceptions about their child's ASD and the impact of these beliefs on parental behaviour and well-being. Future research should consider other robust methods of examining perception and consider the impact of parental perception over time. This may prove valuable for informing and improving clinical practice.

Declaration of interests

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Chapter 2

A Q methodological exploration of caregivers' beliefs regarding their child's Asperger's Syndrome

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Abstract

Asperger's syndrome (AS) is a neurodevelopmental disorder affecting approximately 1% of the population. Developing an understanding of how parents make sense of their child's AS is becoming increasingly important, as research has shown that parental beliefs can affect their decisions regarding treatment, immunisation status and psychological well-being. The present study aimed to identify different caregiver accounts of their child's AS using Q methodology. Twenty-one participants were recruited from a child and adolescent mental health service. Factor analysis revealed four distinct factors: (1) *AS in a positive light*, (2) *AS- the default diagnosis*, (3) *AS- what now?* and (4) *AS as society's problem*. This study demonstrates that Q methodology is a useful tool for determining caregiver perspectives within a clinical setting. The clinical implications of such findings are discussed.

Keywords

Q methodology; parent; caregiver; perception; belief; Asperger's syndrome; ASD

A Q methodological exploration of caregivers' beliefs about their child's Asperger's Syndrome

Asperger's Syndrome (AS) is a neurodevelopmental disorder characterised in the international classifications of mental disorders and diseases as impairments in social interaction, restricted interests, and repetitive and stereotypical behaviours (DSM-IV; American Psychiatric Association, 2000). AS belongs to the broader category of Autism Spectrum Disorders (ASD) along with Autism and Pervasive Development Disorder not otherwise specified (PDD-NOS) (Epstein, Saltzman-Benaiah, O'Hare, Goll & Tuck, 2008). It is estimated that as many as 1 in every 100 children have an ASD in the UK, translating to more than 13 million children in 2001 (The National Autistic Society (NAS), 2013). Services have experienced an increase in the number of referrals looking for assessment and support in the management of people with AS. Stiefel, Shields, Swain, & Innes (2008) observed a 14% increase in the number of referrals for an assessment of AS between 2002 and 2007. The authors of this review suggest that this increase may be as a result of increased awareness of the disorder among the clinical and general population.

There are wide variations in symptom severity among children with AS (Cappe Wolff, Bobet, René & Adrien, 2011) and psychiatric co-morbidities are common (Gaspar de Alba & Bodfish, 2011). The National Autistic Society campaign report 'You need to know' (2010) estimated that the prevalence of ASD within the CAMHS¹ population is about 10% (citing a paper by Wistow & Barnes, 2009). Children and young people with AS can exhibit disruptive behaviours, are difficult to manage

¹ Child and Adolescent Mental Health Service

(Myers, Mackintosh and Goin-Kochel, 2009) and often experience difficulties within social and educational contexts (Stiefel et al., 2008). The specific cause of AS is unknown, thus a variety of aetiological hypotheses remain (Cappe et al., 2011).

Research has consistently demonstrated the impact of having a child with ASD on the family. A number of different sources of stress in relation to parenting a child with ASD have been identified, including the behaviour and development of the child, the cause of ASD, the provision of appropriate services and worries about the future (e.g. Hall & Graff, 2010; Myers et al. 2009). Once a diagnosis has been obtained, for many parents their stress continues to rise as they attempt to adapt and adjust to the changes imposed on their family (Blackledge & Hayes, 2006). Parents of children with disabilities are known to experience emotional distress, interpersonal difficulties and increased family demands (Gupta & Singhal, 2004). Accepting the prognosis of their child's ASD can be difficult for many parents and a lot of time and resources can be spent on searching for a cure (Gupta, 2010). Increasing our understanding of how AS impacts on the family and how the family understands their child with the disorder is important to ensure that families receive the appropriate support relative to their own situation.

When faced with child illness or disability, research has shown that parents often examine their own beliefs in an attempt to make sense of their child's disorder (e.g. King, Zwaigenbaum, King, Baxter & Bates, 2006). It is been proposed that, in doing this, parents construct a representation of their child's disorder to assist them in adapting to the changes placed on the family, adjusting to diagnosis, gaining a sense of control over their situation and making decisions about treatment (Al Anbar,

Dardennes, Prado-Netto, Kaye & Contejean, 2010). The self regulation model purports that illness representations are structured around five components (Leventhal and Diefenbach, 1996): identity, incorporating beliefs about the nature of the disorder (diagnosis, symptoms); cause, perceptions of the underlying cause of the disorder; timeline, the perceived time course of the disorder (long-term, acute, cyclical); consequence, including the personal impact of the disorder on the person or the family; and cure/control, perceptions of how best to manage the illness. The self regulation model has also been extended to include beliefs regarding medication and emotional representations (Horne and Weinman, 2002; Jessop and Rutter, 2003).

A number of questionnaires have been developed to investigate beliefs about illness (e.g. The Illness Perception Questionnaire, Weinman, Petrie, Moss-Morris, & Horne, 1996; Implicit Models of Illness Questionnaire (Turk, Rudy, & Salovey, 1986). One study utilised the IPQ with parents of children with ASD and found significant relationships between illness perceptions and treatment choices, such that those parents who viewed ASD as a serious disorder utilised educative methods and those parents who considered ASD to be unpredictable utilised drugs more frequently. Higher hereditary beliefs were associated with attendance at training programmes and a higher sense of personal control was associated with reduced use of nutritional or drug treatments (Al Anbar et al. 2010).

Research has predominantly focused on the negative assumptions and beliefs held by parents of a child with a disability, with positivity being somewhat neglected (Gupta & Singhal, 2004). However, parental beliefs have been found to have a protective role, for example, hope and spiritual beliefs may help promote resilience among families and help them to adapt to their situation (King et al. 2006). In the physical

health literature, research has shown that attributing positive meaning to their situation assists parents in adapting to their child's chronic health condition (Kazak, McClure, Alderfer, Hwang, Crump, Le, et al., 2004). Parents may attribute a similar meaning when adapting to their child's diagnosis of AS; however, the cognitive representations of parents' understandings of ASD are seldom researched.

It has been recognised that the use of a questionnaire to assess a person's illness perceptions may constrain the range of possible beliefs pertinent to each individual and, thus, reduce the richness of data provided (Jessop and Rutter, 2003). Furthermore, when considering the illness representations of individuals, it is the whole dynamic of representations that are considered important and not the individual item responses. It has been recommended that in order to encapsulate the entire illness perception of an individual, then an approach that involves cluster analysis or factor analysis will be required (Skinner, Howells, Greene, Edgart, McEvilly et al. 2003).

Qualitative research has also been used to capture parental perspectives of ASD. In examining the belief systems of families using focus groups, King et al (2006) found that parents place emphasis on the positive experience of raising a child and value the role that their beliefs play in enabling them to develop a sense of control and coherence over their situation. For other parents, they hold onto the belief that their child will outgrow the disorder (Dale, Jahoda & Knott. 2006). These studies illustrate the differing perspectives that parents hold regarding their child's ASD, however, qualitative investigations are carried out with a small sample and the results cannot be generalised to the wider population. Furthermore, qualitative investigations, although subjective, tend to focus on particular aspects of beliefs and do not always take into

consideration the spectrum of factors that parents may perceive to be relevant to them. This suggests that further investigation of parental perspectives is required. Such research may bring value to services working with children with AS and their families in establishing their subjective experience and beliefs and providing effective interventions and individualised support.

Aim

The aim of the present study was to develop previous findings by investigating the understandings that caregivers' have of their child's AS using Q methodology. This robust approach combines the rigour of quantitative data with the richness of qualitative data (Spurgeon, Humphreys, James & Sackley, 2012) and provides holistic viewpoints that are psychologically significant to each individual (Watts & Stenner, 2012). The way in which caregivers' understand their child's disorder may affect how they relate with their child and engage with services. Elucidating the range of perceptions held by caregivers' may help health care professionals and researchers recognise gaps in parental knowledge about AS, as well as unravelling potentially unhelpful beliefs or misunderstandings about the disorder.

Methods

Overview of Q methodology

Q methodology (Q) is a mixed qualitative-quantitative methodology that has been identified as a useful tool for researching a person's subjective beliefs, experiences and perspectives (Shinebourne, 2009). Q is exploratory, theory generating and enables the development of a range of perspectives (Stenner, Dancey & Watts, 2000). It does not impose *a priori* meanings (Coogan & Herrington, 2011) and is considered to be a

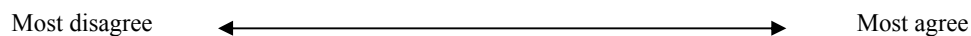
more sensitive method for obtaining data than interviews and surveys (Bryant, Green & Hewison, 2006). A full review of Q methodology is beyond the scope of this study, however, several are available (e.g. Shinebourne, 2009; Watts & Stenner, 2012).

Development of statement concourse (Q set): “Perceptions of Asperger’s syndrome”

The first phase of Q involves the development of the concourse, or Q set, representing a diverse range of perspectives of AS. Information used to generate statements for the Q set in the present study was elicited from a literature review using bibliographic databases, including PsycINFO and Medline, as well as a review of online parent forums, newspaper articles and books. Discussions also took place with a consultant clinical psychologist with a special interest in AS. An initial collection of 114 statements was generated from the search representing the diverse views of AS. A broadly representative subset of statements was then placed within the dimensions of the illness perception model (Leventhal and Diefenbach, 1996), focused around causal factors, identity and symptom-related factors, consequence factors, cure/control factors, timeline factors and treatment-related factors. Other dimensions also emerged from the literature search, including positive aspects of AS and societal views. The initial sample of 114 statements was refined to 51 statements following feedback from various professionals including two clinical psychologists, psychology lecturer, educational psychologist, learning support teacher and three trainee clinical psychologists. Duplicate items were removed and complex expressions were re-phrased. Where possible, statements were based on quotations from the literature/forums, using comprehensive wording to reflect a more insightful viewpoint. The Q set is presented in Table 2.4. In preparation for the sorting task, each statement was written on a separate card and randomly assigned a number.

Sorting procedure

The Q sort is the central research tool of Q (Bryant et al., 2006). Q sorting requires participants to read the statements (Q-set) and arrange them according to an evaluative profile (in the case of the present study, a profile ranging from ‘agree’, through ‘neutral’ to ‘disagree’), before sorting them along a predefined quasi-normal distribution grid according to how the statements reflect their point of view. The grid used in the present study ranged from +6 (strongly agree) to -6 (strongly disagree) (see Figure 2.1). Using a forced normal distribution helps to reveal participants preferences in a thoughtful way (Webler, Danielson & Tuler, 2009). On completion of the sorting process, data were recorded by the first author onto a response matrix. Each participant was asked to comment on those statements they ranked at each end of the dimension (e.g. +6/-6) and offered the opportunity to comment on items that were not clear. This information was used to aid the interpretation of results.



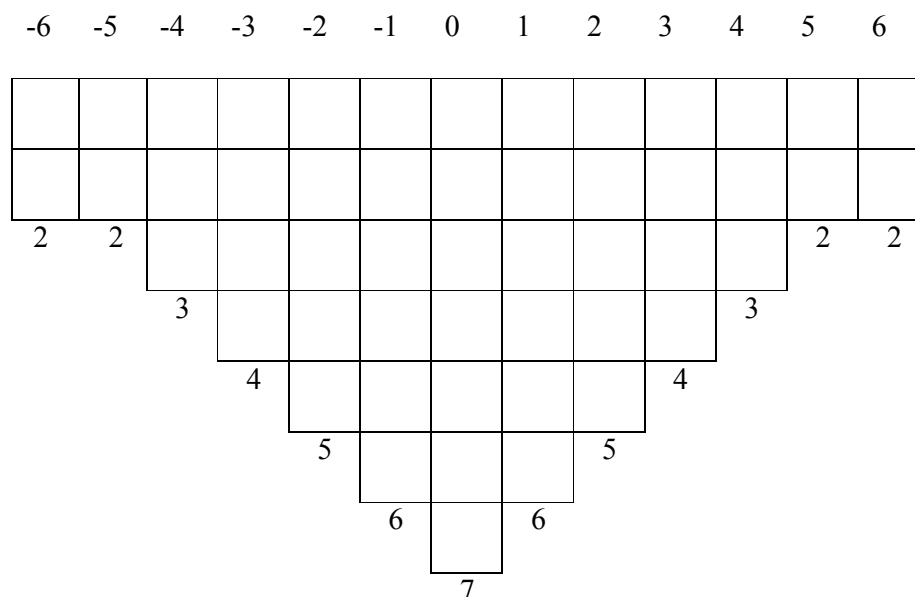


Fig 2.1 Example of the pre-arranged frequency distribution grid, designed for use with a set of 51 statements.

Recruitment

Sixty information packs containing a research invitation letter, information sheet and consent form (see Appendices 5 to 7) were distributed to clinicians within six locality CAMHS teams in central Scotland to be shared with potential participants. The study was also advertised in a 'HOPE for Autism' support group newsletter and the first author attended one group to discuss the research with those parents in attendance; providing 30 information packs. The exact number of information packs given to or collected by potential participants is unknown. As the aim of Q is to explore diversity of perception and understanding rather than prevalence, randomisation of participants for statistical representation was not required (Watts & Stenner, 2012). Inclusion criteria for participation in this study required that participants were the parent(s) or

main caregiver(s) of a child with a confirmed diagnosis² of AS. Within Q, the Q-set constitutes the sample, with participants becoming study variables; thus, large numbers of participants are not required to sustain a robust study (Watts & Stenner, 2012). A 1:3 ratio has been recommended within Q research, one participant required for every three Q-statements; with many studies involving between 12 and 20 participants (Webler et al., 2009). The present study, therefore, aimed to recruit a minimum of 17 participants.

Procedure

Participants were invited to contact the first author should they be interested in taking part in the study. Once contact had been made, participants were invited to meet with the first author for one hour, in an interview-based setting, at the local Child and Family clinic to participate in the study. Participant consent was reviewed again at this point and any questions about the study were addressed. Participants were then provided with a research pack containing Q-statements and distribution grid, instructions on how to complete the grid, and four self-report measures.

Participants

Twenty-one parents/main caregivers of children with AS participated in the present study. All participants were recruited through CAMHS. Demographic information for participants is presented in Table 2.1. Seventy-six per cent of participants were female. The sample included 14 biological mothers, 3 biological fathers, 1 step-father, 1 grandmother, 1 grandfather and 1 sister; all of whom were the main carers of a child with AS. Three couples participated in the study and one mother-sister dyad (all

² Those children with a confirmed DSM-IV (Diagnostic and Statistical Manual of Mental Disorders 4th Edition) or ICD-10 (International Classification of Diseases 10th Edition) diagnosis of AS.

participants independently completed their own Q sort and measures). Participants ranged in age from 19-55 years with an average of 37.7 years. Over half of participants were unemployed. The majority of participants (80.9%) received follow up support following their child's diagnosis and continued to receive support from a number of services, including CAMHS (70.6%), Speech and Language Therapy (11.8%), Occupational Therapy (11.8%) and Educational Psychology (11.8%). Approximately one-fifth of participants currently attended support groups.

Table 2.1 Participant Demographic Characteristics (N=21)

Characteristic	N (%)
Relationship to child	
Mother	14 (66.7)
Father	3 (14.3)
Step-parent	1 (4.8)
Grandparent	2 (9.5)
Sibling	1 (4.8)
Age	
Mean (SD); Range	37.7 years (8.95); 19-55 years
(Missing values)	1 (4.8)
Marital status	
Married/co-habiting	20 (95.2)
Single	1 (4.8)
Current employment status	
Employed F/T; P/T	5 (23.8); 4 (19)
Unemployed	12 (57.1)
Number of other children¹	
Mean (SD)	1.24 (0.86)
Range	0-3
Support received following diagnosis	
Follow up from diagnostician/service	17 (80.9)
Written information with no follow up	3 (14.3)
None	1 (4.8)
Current support from Services¹	
CAMHS	12 (70.6)
Occupational Therapy	2 (11.8)
Speech and Language Therapy	2 (11.8)
Educational Psychology	2 (11.8)
Other	ICS: 2 (11.8); Dietician: 1 (5.9); Health Visitor: 1 (5.9)
None	3 (17.6)

Table 2.1 Participant Demographic Characteristics (N=21) continued

Characteristic	N (%)
Attend support groups	
Yes	4 (19)
No	17 (80.9)
Information resources used	
Reading	20 (95.2)
Professionals	15 (71.4)
Workshops/seminars	3 (14.3)
Conferences	1 (4.8)
Internet	18 (85.7)
Support groups	4 (19)

Abbreviations: SD: Standard deviation; CAMHS: Child and Adolescent Mental Health Service

¹Three couples and one mother-daughter dyad participated in the study. To prevent the same data being included in the above descriptives, only the information from one parent/caregiver was utilised (N=17).

Table 2.1 Participant Demographic Characteristics (*continued*)

Demographic information regarding participants' children with AS is reported in Table 2.2. Twelve male children and 5 female children were included in the sample, giving a ratio of 2.4:1. Children ranged in age from 5 to 17 years with an average age of 10.3 years. There was a large range in length of diagnosis of AS from 1 month to 10 years. The majority of children were in mainstream education (88.2%). Psychiatric co-morbidity was present in approximately half of the children, the most common of which was Attention Deficit Hyperactivity Disorder (ADHD) (41.2%).

Table 2.2 Child with Asperger syndrome demographic characteristics (N=17)¹

Characteristics	N (%)
Gender	
Male	12 (70.6)
Female	5 (29.4)
Age	
Mean (SD)	10.3 years (3.26)
Range	5-17 years
Length of diagnosis	
Mean (SD)	23.5 months (31.6)
Range	1-120 months
Where received diagnosis	
CAMHS	14 (82.4)
Specialist ASD diagnostic service	1 (5.9)
GP	1 (5.9)
Other	Hospital paediatrician: 1 (5.9)

Table 2.2 Child with Asperger syndrome demographic characteristics (N=17)¹
continued

Characteristics	N (%)
Current school provision	
Mainstream	15 (88.2)
Special Educational Needs	1 (5.9)
Both	1 (5.9)
Co-morbid psychiatric condition	
Yes	8 (47.1)
	ADHD: 7 (41.2); Low mood: 1 (5.9); anxiety disorder: 1 (5.9)
No	9 (52.9)

Abbreviations; ADHD: Attention Deficit Hyperactivity Disorder

¹ The sample of participants included three couples and one mother-sister dyad; therefore, the demographic information provided above reflects that of 17 children.

Measures

The following measures were administered in order to situate the sample.

Demographic information

An ad hoc questionnaire was developed for the purpose of this study to obtain data regarding participant age, family composition, employment status, and sources of support. The questionnaire also sought information on sex, age, and educational establishment of the child with AS.

Parenting Stress Index Short Form (PSI-SF; Abidin, 1995)

PSI-SF is a 36-item derivative of the Parenting Stress Index (Abidin, 1983) frequently used in research with parents of children with ASD. Parents respond to statements on a 5-point Likert-type scale (strongly agree to strongly disagree). The questionnaire yields an overall score that reflects total stress related to the parenting role. A number of studies have found the PSI-SF to demonstrate adequate test-retest reliability,

internal consistency and construct validity (e.g. Haskett, Ahern, Ward & Allaire, 2006). A score at or above the 85th percentile is considered ‘high’ (Epstein et al., 2008).

General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988)

GHQ-12 is a 12-item measure of general well being that reliably screens for general psychiatric problems. Items were scored using the GHQ scoring method (0-0-1-1). In a study of the general population, the GHQ-12 demonstrated good internal consistency (Cronbach’s alpha 0.76) and external and structural validity (0.57 to 0.75) (Sánchez-López & Dresch, 2008). Scores of 3 or above demonstrate ‘caseness’ of a psychiatric disorder with 73% sensitivity and 83% specificity (Cano, Sprafkin, Scaturo, Lantinga, Fiese & Brand 2001).

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

SDQ is a 25-item questionnaire completed by parents to assess the psychological adjustment of their child. Items are scored using a 3-point Likert scale. A *total difficulties score* was generated by summing all items scores (minus the prosocial items). The measure has demonstrated good sensitivity (63.3%) and specificity (94.6%) in screening for psychiatric disorders among 5-15 year olds (Goodman, Ford, Simmons, Gatward & Meltzer 2000) as well as good test-retest reliability (0.76), concurrent validity (0.76), internal consistency (0.80) and discriminant validity (0.87) (Stone, Otten, Engels Vermulst & Janssens, 2010).

Ethical procedures

The study was granted ethical approval from a local NHS Research Ethics Committee (see Appendix 8), Research & Development department (see Appendix 9) and the

University of Edinburgh Clinical Psychology Research Ethics Committee. The study was also registered with the local NHS CAMHS Clinical Governance Group.

Data analysis

The 21 completed Q sorts were analysed using an established statistical software package, PQ Method version 2.33 (Schmolck, 2012). This program subjects data to a by-person, rather than by-item factor analysis, showing similarities in the way in which participants sort statements. Following the inter-correlation of completed Q sorts (i.e. 21x21 matrix), centroid factor analysis was performed, followed by varimax rotation. The indeterminacy of its solutions makes the centroid method the preferred choice of factor extraction in Q (Watts & Stenner, 2012). The analysis was run with the maximum extraction of factors enabled by PQ method (7 factors) and factors with eigenvalues of >1 and at least one significantly loading Q sort were selected for further interpretation (Stenner et al., 2000). This resulted in 4 factors being extracted, accounting for 54% of the study variance. Out of the 21 completed Q sorts, 15 loaded significantly (± 0.38 , $p < 0.01$) and uniquely onto one of these 4 factors (see Table 2.3). These Q sorts are known as ‘factor exemplars’.

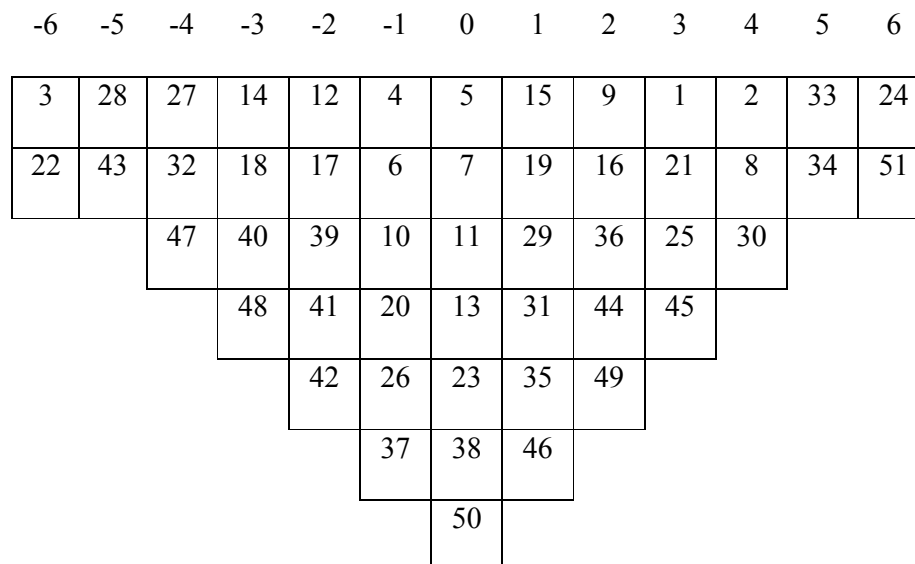
Table 2.3 The rotated factor matrix with X indicating a defining sort

Q Sorts	Factor 1	Factor 2	Factor 3	Factor 4
1	0.20	0.11	0.72X	0.00
2	0.34	0.09	0.67X	0.25
3	0.48	0.01	0.28	0.57
4	0.22	0.05	-0.08	0.72X
5	0.37	0.37	0.46X	-0.05
6	0.74X	0.27	0.14	0.19
7	0.14	0.37	0.47X	-0.05
8	0.41	0.19	0.48	0.20
9	0.23	0.40X	0.38	0.11
10	0.48X	0.28	0.28	0.33
11	0.34	0.13	0.39	0.44

Table 2.3 The rotated factor matrix with X indicating a defining sort continued.

Q Sorts	Factor 1	Factor 2	Factor 3	Factor 4
12	0.62X	0.13	0.34	0.34
13	0.62X	0.12	0.18	0.26
14	0.07	0.02	0.69X	0.36
15	0.68	0.09	0.44	0.26
16	0.20	0.03	0.41X	0.01
17	0.56X	0.31	0.38	0.12
18	0.29	0.49	0.11	0.40
19	0.20	0.96X	0.06	0.10
20	0.39	0.29	0.24	0.50
21	0.56X	0.23	0.31	0.19
% expl. Var.	18	10	16	10

To aid in the interpretation of factors, factor exemplars were merged to generate a composite ‘ideal’ Q sort for each factor, known as the factor array. Factor arrays, thus, represent those participants with a similar sorting pattern and a particular perception of AS. Factor arrays are presented in Table 2.4 and an example of a ‘hypothetical’ Q sort, or factor array, is illustrated in Figure 2.2.

**Fig 2.2** An example of a factor array (Factor 1)

Interpretation of the data in Q involves a pattern analysis of items in the factor arrays. In this analysis, particular attention was given to statements ranked at the extremes (e.g. 'strongly agree', 'strongly disagree'), as well as distinguishing and consensus statements and participants' explanations, to aid in the interpretation of factors. This is a hermeneutic process, providing a narrative account of each factor, and involves a degree of subjectivity (Shinebourne, 2009; Stenner et al., 2000).

Table 2.4 Factor arrays demonstrating the consensus ranking of statements for each Factor (1-4)

No.	Q set statements	Factor Arrays			
		1	2	3	4
1	I felt relieved when my child was given a diagnosis of AS	3	-2	5**	1
2	I feel lucky to have such a unique child	4	-1	1	3
3	I have a child with AS because God chose me	-6	-6	-1	0
4	I often make excuses for my child's behaviour rather than explain to people that my child has AS	-1	2	2	-4
5	I will never understand how my child thinks about the world	0	0	2	-5**
6	My child was diagnosed with AS because no one knew what was wrong	-1	5**	-6**	0
7	My child's disorder is a serious condition	0	1	1	1
8	I have a clear picture or understanding of my child's AS	4**	-2	-2	-2
9	AS has major consequences for my child's life	2	4	2	-2**
10	My child's disorder is very unpredictable	-1	1	3	0
11	My child's disorder does not worry me	0*	-2	-4	5**
12	My child developed AS following a reaction to a childhood vaccination	-2	-3	-5	0
13	Nothing I do will affect my child's AS	0	0	0	1
14	AS is something my child will grow out of	-3	-3	-6*	-1
15	When I think about my child's disorder I often get upset	1	3	3	-2
16	My child's AS strongly affects the way others see them	2	2	5	4
17	My child's AS does not have much affect on his/her life at the moment	-2	-3	-4	-1
18	Stress or worry contributed to the development of my child's AS	-3	-2	-2	-4
19	Treatment can control my child's AS	1	0	-3*	0
20	It's all down to chance or luck who develops AS	-1	-4*	0	0
21	Other children are just as demanding as children with AS	3	2	2	-4**
22	Children with AS are unable to show love	-6	-4	-3	-6
23	I feel judged as a 'bad' parent by society	0	-1	4	5
24	I get a lot of joy from my child with AS	6*	0	4	2
25	I view my family as the same as any other	3	6	1**	-3**
26	AS is a physical illness	-1	3	-5**	0
27	Complications during pregnancy caused my child to develop AS	-4	0	-3	-3

Table 2.4 Factor arrays demonstrating the consensus ranking of statements for each Factor (1-4) (*continued*)

No.	Q set statements	1	2	3	4
28	My child's difficulties are behavioural and are not due to an inherent disorder	-5	1	-2	-1
29	My child's diagnosis of AS does not explain all their difficulties	1	4	-2*	2
30	I sometimes overprotect my child with AS	4	2	4	-1
31	I don't like to discipline my child as they cannot control their behaviour	1	-4*	-1	1
32	I feel like I will never get to know my child	-4	-5	0	-1
33	I could not have prevented my child from developing AS	5	1	3	3
34	The diagnosis of AS helps me to understand my child and their behaviour	5*	1*	6*	-3*
35	Asperger's syndrome is hereditary-it runs in the family	1	4	-1**	4
36	Raising a child with AS is a stressful experience	2	5	6	2
37	Vitamins and supplements help my child with AS	-1	-1	0	1
38	I sometimes wish that doctors would prescribe my child medication for their AS	0	-1	0	-5*
39	I have no interest in finding out the cause of my child's AS	-2	-2	-3	1
40	My child's behaviour embarrasses me sometimes	-3*	2	1	-6*
41	I am having trouble accepting my child's diagnosis of AS	-2	-3	-2	-3
42	I feel more like a carer than a parent	-2	3	-1	4
43	My own behaviour contributed to the development of my child's AS	-5	0	-4	-2
44	I appreciate life more due to having a child with a disorder	2	-1	0	2
45	I believe I am a better parent because of my child with AS	3	3	0*	3
46	I believe there may be some eventual benefits for me having a child with AS, even if it is not apparent at this time	1	-1	1	2
47	I continue to search for a magical cure	-4	-6*	-1	-2
48	I find it difficult not to blame myself for what has happened	-3	0	3**	-1
49	There is nothing wrong with my child, it is what society expects of them that is wrong	2	1	2	3
50	My child can lead a full and independent life	0*	-5**	-1*	6**
51	Having a child with AS is a positive learning experience	6	6	1**	6

Statements were ranked from +6 = strongly agree to -6 = strongly disagree

Distinguishing statements are indicated with * (p<0.05) (** indicates significance at p<0.01).

Results

Descriptive statistics

Twenty participants completed the GHQ-12, SDQ and PSI-SF. The means, standard deviations and ranges are reported in Table 2.5. Sixty per cent of participants met criteria for a psychiatric disorder as measured by the GHQ-12 (M=4.95, S.D=4.01). The majority of participants (95%) reported their child's difficulties to be within the 'very high' range on the SDQ (M=25.55, S.D=5.31). Based on the Total Stress score of the PSI-SF, 83% of participants reported high stress levels, scoring within the clinically significant range (M=103.94, S.D=19.22). Two participants indicated defensive responding on this measure; therefore, their results were not included.

Table 2.5 Means and standard deviations (SD) for psychometric measures (N=20)^a

Measure	Mean	SD	Range	Additional comments
GHQ 12	4.95	4.01	0-11	60% met threshold for psychiatric disorder (cut off=3)
SDQ (Total Difficulty Score)	24.55	5.31	8-36	95% reported child difficulties within the 'very high' range
PSI-SF (Total Score) ^b	103.94	19.22	81-146	83% met clinical threshold (>85 th percentile)

PSI-SF: Parenting Stress Index-Short Form; GHQ: General Health Questionnaire 12 item; SDQ: Strengths and Difficulties Questionnaire.

^a One parent did not complete the measures above; therefore the results are based on 20 participants.

^b PSI-SF scores for two parents indicated defensive responding, therefore, were not included in results (N=18).

Narrative interpretation of each merged Q-sort factor

Consensus statements

Q revealed nine consensus statements whose ranking did not distinguish between any pairs of factors. All participants agreed with the statements: *my child's disorder is a serious condition* (7); *nothing I do will affect my child's AS* (13); and *there is nothing*

wrong with my child it is what society expects (49). Participants disagreed with the statements: *my child's AS does not have much affect on his life* (17); *stress or worry contributed to the development of AS* (18); and *I am having trouble accepting my child's diagnosis of AS* (41). Rankings for the remaining consensus statements varied (positive and negative rankings), however, the difference was not significant to discriminate between factors: *vitamins and supplements help my child with AS* (37); *I appreciate life more due to having a child with a disorder* (44); and *I believe there may be some eventual benefits for me having a child with AS even if it is not apparent now* (46). As these statements did not discriminate between factors, they were not considered within the factor interpretations.

Factor 1: AS in a positive light

The Q-sorts of six participants loaded significantly and uniquely onto Factor 1, making it the largest of the four factors. Factor 1 accounted for 18.5% of the variance (Eigenvalue (EV) = 3.9). Participants consisted of two biological fathers, one stepfather, one grandfather, a biological mother and one grandmother. Three participants had male children and three had female children with AS. Children ranged in age from 5 to 13 years and the average length of diagnosis was 2.4 years (range 10 months to 5 years). Four children had co-morbid ADHD and were on medication. One participant did not complete psychometric measures, therefore, is not included in the following psychometric results. Factor 1 exemplars had 'very high' stress scores ($M=101.50$, $S.D.=13.18$). One participant indicated defensive responding on the PSI-SF; therefore, their results are not included in this mean. Two participants out of five demonstrated 'caseness' for a psychiatric disorder. Child difficulties were reported to be within the 'very high' range ($M=26.0$, $S.D.=3.24$).

Factor 1 exemplars see value in their child's diagnosis, strongly agreeing with the statement that AS helps them to understand their child's difficulties (34: +5). They are able to draw upon positive aspects of having a child with AS in terms of personal gains, agreeing with statements that raising a child with AS is a positive experience (51: +6) and that they are better parents because they have a child with AS (45: +3). Factor 1 exemplars also perceive their child with AS in a positive light, agreeing with the statements that they get a lot of joy from their child (24: +6) and feel lucky to have such a unique child (4: +4). Factor 1 exemplars also consider themselves to have a good understanding of AS (8: +4) and view it as an "on going journey" (Participant 13).

Participants in this factor are overprotective of their child with AS (30: +4) and strongly reject the statements that children with AS are unable to show love (22: -6) or that their child's difficulties are behavioural and not due to an inherent disorder (28: -5). Although religious beliefs were not directly explored in this study, there is a strong disagreement among Factor 1 exemplars that they were chosen by God to raise a child with AS (3: -6). They also reject the notion of blame, with exemplars agreeing that they could not have prevented the development of AS (33: +5) and disagreeing with the statement that their behaviour contributed to it (43: -5). For Factor 1 exemplars, "AS becomes part of life" (Participant 6) and they do not spend their time trying to change their situation, disagreeing with the statement that they search for a magical cure (47: -4).

Factor 2: AS - the default diagnosis

Two participants, 9 (0.40, $p < 0.01$) and 19 (0.96, $p < 0.01$) were associated with Factor 2. Factor 2 accounted for 10% of variance ($EV = 2.15$). Both participants were female (one mother; one sister) with male children with AS aged 7 and 17 years respectively. Length of diagnosis was 10 months and 10 years. One child had co-morbid ADHD and one child had low mood and anxiety. Both children were taking psychotropic medication. Both participants met caseness for a psychiatric disorder. Child reported difficulties were in the 'very high' range ($M = 24.0$, $S.D. = 1.41$) and parenting stress was significantly high ($M = 124.50$, $S.D. = 17.68$).

In line with Factor 1, Factor 2 exemplars perceived having a child with AS to be a positive learning experience (51: +6), however, two statements distinguish Factor 2 from other factors. Firstly, participants in this factor were strongly of the view that their children were diagnosed with AS as no one knew what was wrong with their child (6: +5). In other words, the children were diagnosed by default. Factor 2 exemplars believe there is something else to explain their child's difficulties, agreeing with the statement that the diagnosis does not explain all of their child's difficulties (29: +4). One participant disagrees with their child's diagnosis altogether, stating that she does not believe her child has AS (Participant 19). These participants did not view the diagnosis as particularly helpful for their child, with Participant 19 believing that her child "acts up to the diagnosis". The diagnosis is also considered to be detrimental in terms of how others view their child, with Participant 9 considering her child to be "more capable than what others give him credit for". Factor 2 exemplars consider their family to be like any other (25: +6), however, they agree with the statement that parenting a child with AS is a stressful endeavour (25: +6) and strongly disagree with

the view that their child will be able to lead a full and independent life (50, -5). Although Factor 2 exemplars may disagree with their child's diagnosis of AS, they are clearly concerned about the long term impact of their child's difficulties and are aware of the stressful burden it places on them as caregivers; thus, distinguishing Factor 2 from other factors.

Factor 3: AS-What now?

Six participants loaded significantly and uniquely upon Factor 3. Factor 3 accounted for 16% of variance ($EV = 3.41$). All participants were mothers; three had male children and three had female children with AS. Children were aged between 5 and 13 years and the average length of diagnosis was 6 months (range 1 to 14 months). Three participants met caseness for a psychiatric disorder. Child difficulties were rated very highly ($M=27.17$, $S.D=4.88$), as well as parenting stress ($M=121.0$, $S.D=11.81$). One participant indicated defensive responding on the PSI-SF, therefore, was not included in this result.

Like Factor 1, Factor 3 exemplars firmly believe in their child's diagnosis, strongly disagreeing with the statement that their child was diagnosed with AS as no one knew what was wrong (6: -6). For Factor 3 exemplars, a diagnosis was met with a strong sense of relief (16: +5), as they are now better able to understand their child and their difficulties (34: +6). A diagnosis also brings the realisation that their child has a life-long condition, with Factor 3 exemplars strongly disagreeing with the statement that AS is something their child will grow out of (14: -6). As one participant commented, "a diagnosis helps us understand our child but it doesn't change the situation or make it any better" (Participant 1). Unlike Factor 1, Factor 3 exemplars hold a negative

view of having a child with AS, strongly disagreeing with the statements that AS does not worry me (11: -4) and agreeing with the statements that they get upset when thinking about their child with AS (15: +3) and that raising a child with AS is a stressful experience (36: +6). Factor 3 exemplars also raise concern as to how their child is perceived by others, strongly agreeing with the statement that AS affects the way others see their child (16: +5). Factor 3 exemplars consider possible causes for their child's AS more than other factors, strongly disagreeing with the statement that a childhood vaccination contributed to the development of AS (12: -6) or that AS is a physical illness (26: -5). These exemplars also slightly disagree with the statement that AS is hereditary (35: -1), however, hold some element of blame for their child's AS (48: +3).

Factor 4: AS as society's problem

One participant, a mother of a male child aged 9 years with AS, loaded significantly and uniquely onto factor 4 (0.72, $p < 0.01$). Factor 4 accounted for 10% of variance (EV = 2.15). The length of diagnosis was 1 year. This participant did not meet caseness for a psychiatric disorder and reported stress was in the normal range (75-80th percentile). Child difficulties were reportedly very high (SDQ score 28) and the child had co-morbid ADHD. This participant also has an adult child (>18 years) with AS.

Similar to Factor 1 and 2, the exemplar of Factor 4 perceives having a child with AS to be a positive learning experience (51: +6). A salient feature of Factor 4, however, is the impact of society's view of her and her child. Factor 4 exemplar strongly feels judged as a bad parent by society (23: +5), which may be a reflection of how she and

her child have been treated within society. There is a strong disagreement with the statement my child's behaviour embarrasses me (40: -6), again suggesting that this participant has perhaps had to defend and stand up for her child against the negative view of others. It is likely that Factor 4 exemplar's experience of having raised another child with AS has influenced her perception of her younger child's AS. For example, Factor 4 exemplar strongly disagrees with the notion that she will never understand how her child thinks about the world (5: -5). She holds high expectations for her child's future, agreeing with the statements that my child's AS does not worry me (11: +5), my child will lead a full and independent life (50: +6), and disagreeing with the statement that AS has major consequences for my child's life (9: -2). Factor 4 exemplar has found benefits in using "gluten-free diets" with her child with AS, however, strongly disagrees with giving medication to her child (38: -5).

Discussion

This study aimed to explore parental perceptions regarding their child's AS and is the first to apply Q methodology with this population. Four accounts were identified and described qualitatively: (1) *AS in a positive light*, (2) *AS- the default diagnosis*, (3) *AS- what now?* and (4) *AS as society's problem*. These findings will be considered within the context of participant demographics and previous research. Reflection on the utilization of Q will be acknowledged as well as consideration for future research.

Participants in this study demonstrated a broad and comprehensive understanding of AS and reported mainly positive views regarding AS. Other studies, also recruiting from clinical samples, have shown that parents' optimism about their child's ASD is often guarded (e.g. Dale et al. 2006). The rejection of causal factors such as stress and

vaccinations and, for the majority, acceptance of hereditary links in the current study indicates that participants hold views in line with current research and clinical practice. These may be a reflection of the diagnostic follow-up support that the majority of participants (80%) in this study received; however, other recent studies have found similar results. Drawing upon the self-regulation theory, Al Anbar et al. (2010) adapted the IPQ to the autism population and found that parents most frequently cited a genetic cause for their child's autism. These findings may suggest that the perception of aetiological factors of AS may be changing as a whole.

The first factor, in particular, maintained a broadly positive view of AS, placing emphasis on their child's strengths as well as personal gains of having a child with AS. Several theories propose that successful adjustment to a traumatic event initially involves making sense of the situation and then exploring the benefits of the situation (e.g. Janoff-Bulman, 1992, as cited in Pakenham, Sofronoff & Samios, 2006; Myers et al. 2009). It could, thus, be hypothesized that those caregivers represented by Factor 1 have come to terms with having a child with AS and maintaining a positive perception is their way of coping with this. What is of particular interest about this factor, however, is the predominance of male participant loadings. There is limited research regarding paternal views related to their child's ASD and AS in particular. However, what research has been done showed that men and women respond differently to their child's diagnosis and the results of the current study may be an indication of this difference. In Gray's (2003) study, fathers described themselves as being on the "periphery" and did not feel personally affected by their child's AS. Furthermore, they did not take as active a role as the child's mother in raising their child with AS and considered themselves more as sources of support for their partners. Although this was not addressed in the current study, it could also be

assumed that the positivity of Factor 1 may reflect the different roles adopted by parents when it comes to caring for their child with AS. This is an area that warrants further research.

Factor 2 participants present a view of disagreement with the diagnosis of AS in their children. They hold the view that it does not explain all of their child's difficulties and that their child is now "living up" to the diagnosis. This viewpoint may have made it difficult for participants to complete the Q-sort as statements related to having a child with AS. It is therefore possible that completion was based on their understanding and perception of AS in its true sense, and not based on the perception of AS as related to their child. It is also important to address the fact that one of the participants, loading significantly onto factor 2, was an elder sibling of a child with AS. Although this participant is considered by herself and her family to be the child's main carer, her perception of the child and his diagnosis may have been influenced by their sibling relationship.

Factor 3 consisted of six mothers, the majority of whom had children diagnosed with AS within the previous year. Factor 3 held a mixed tone, whereby participants felt a sense of relief following the diagnosis of AS, however, were then faced with the realisation that their child has a life-long condition that may have significant consequences for their life. The mothers in Factor 3 also present as more emotionally affected by their child's AS than the other Factors in terms of their ranking of emotion-based statements. These findings, together with the relatively short length of diagnosis, suggest that these participants are in the early stage of adjusting to their child's diagnosis. Fleischmann (2004) found similar results in his qualitative study, with parents reporting feeling relieved after their child was diagnosed with ASD,

however, also feeling guilt and anger. It is possible that these perceptions may change over time as these parents begin to adapt and learn to cope with their child's diagnosis. This may be illustrated in the differences between Factors 3 and 4. The participant loading significantly onto Factor 4 was the only participant in the study who also had an older child with AS. It is possible, therefore, that her views and perceptions of AS has changed along with her previous experience. This finding offers support to the self-regulation theory, which suggests that the process of understanding and coping with illness is a dynamic one, where changes in symptoms, knowledge or experience can result in a re-evaluation of perception and a subsequent change in emotional responding and coping (Leventhal and Diefenbach, 1996). Longitudinal research considering the changing perspectives of caregivers over time would be useful in clarifying this further and, perhaps, the adjustment process that families endure when raising a child with a disability.

Strengths of Q

Q has proved a useful tool in exploring the perceptions of caregivers of children with AS. The method was particularly useful with participants who have limited time and resources available to participate in research. Although a questionnaire-based study may have been less time consuming, it would have required a large number of participants and would not have generated the depth, quality and diversity of information obtained by Q.

Participants enjoyed the process of Q sorting and valued the consideration of their personal view. The inclusion of negative statements enabled participants to be honest with their views and address issues that may remain unspoken in other qualitative research settings (Morecroft, Cantrill & Tully, 2006). Q also reduces the impact of

providing socially desirable responses (Papworth & Walker, 2008). Participant feedback indicated that the process helped to clarify their views regarding the causes of AS and re-affirmed their understanding of their child's disorder. For other participants, it allowed them to reflect on views that they had not previously considered.

Study limitations

This study has several limitations that should be acknowledged. Firstly, the recruitment of self-selecting participants from one service (CAMHS) indicates a non-representative sample of the population and subjects the study to sample bias. The small sample size also limits the generalisability of results beyond this study. Furthermore, the results of the current study reflect the views of participants at a single point in time and are not necessarily generalisable beyond that point. However, given that the aim of Q is to extrapolate varying perspectives about a specific experience (Morecroft et al. 2006), the generalisation of findings to the wider population was not of concern.

The perceptions explored within this study can only be considered and understood within the context of the Q-set (statements) utilised. Parents of children with AS were not consulted in the development phase of the Q set. This may have been a useful process in allowing parents the opportunity to reflect on the content to ensure issues considered to be important to them were covered. On reflection of the results, it is possible that the wording of some statements may have resulted in participants responding to their views about AS in general and not specifically ranking the statement in relation to their view about their own child's AS (e.g. statement 35: AS is hereditary). Despite the study not being piloted with the target population, other

professionals independent of the research were involved in reviewing the statements. Furthermore, the researcher was present at all times to ensure any questions regarding statements were adequately addressed. When encouraged to comment on the process, participants viewed the method as comprehensive and the statements relevant to the topic.

The current study utilised a forced-choice quasi-normal distribution grid and a number of participants found it difficult to rank statements that they viewed to have equal ranking at extreme ends of the distribution, stating their preference particularly for an increased number of ‘disagree’ options. Forced choice ranking is, however, the most commonly utilised method of Q (Watts & Stenner, 2012), and is considered to produce the fairest representation of a participant’s viewpoint (Stenner et al., 2000).

Clinical Implications

The results of the current study are important for a number of reasons. Firstly, they highlight the variety of accounts that caregivers hold regarding their child’s AS, despite all participants being recruited from the same child mental health service. These results, thus, indicate a need for clinicians to go a step further in exploring caregivers’ knowledge as well as their beliefs regarding the disorder. Given that previous research has shown parental perceptions to contribute to the process of adaptation and experience of stress (Hambrick, & Ingersoll, 2011), this may be an important target for intervention within clinical settings.

Generating a common understanding of AS lays the foundation on which to build an effective intervention, that is tailored to suit the family. Helping caregivers to re-appraise their situation and focus on their child’s strengths may enable them to view their child’s disorder in a more positive light and strengthen the relationship with their

child (Gupta & Singhal, 2004). Thus, the modification of caregivers' beliefs about their child's AS may signify an important direction for future psychoeducational interventions to work towards (Al Anbar et al. 2010). Given the increasing prevalence of AS within child services, and the increased need for support for families, this is an area that requires frequent consideration and development.

Future directions

It is acknowledged that the current study has not exhausted all possible accounts of AS among parents or main caregivers. Further Q research utilising larger samples may provide further validation of the accounts identified in the current study and characterise other unique viewpoints. Qualitative methods could also be utilised to strengthen and apply greater depth to the perceptions elicited in the current study. Traditional standard variance analytic methods could then be used to determine the prevalence of these viewpoints within a larger population of parents (Morecroft et al. 2006). It would be useful for future research to establish the reliability of perceptions over time by completion of the same Q sort at a later time point. It is likely that a parent's understanding of their child's AS will change over time. Examining a changing perspective may also be particularly fruitful at a time when revisions to the DSM are likely to have an ongoing impact on how the condition is described and treated (APA, 2012).

Further research should be carried out to ascertain whether perspectives differ between clinical and non-clinical populations and investigate possible reasons for any difference. An in-depth exploration of child views regarding their own AS and how they differ from their parents is another important avenue to consider, particularly for those services working with children and their parents. For example, previous

research has shown that young people with ASD perceive their autistic traits and levels of empathy differently than their parents (Johnson, Filliter & Murphy, 2009). This may have significant implications for engaging young people and families in services and with particular types of intervention. Measuring the extent of agreement between families and health care professionals highlights another important area for future research. There remains a gender bias in the parental literature regarding ASD, therefore, the perception of fathers and how they make sense of their child's AS is a key area for further exploration.

Conclusion

This study has been the first to identify dominant narratives that circulate amongst caregivers' of children with AS using Q methodology. This approach is a particularly useful method for capturing key perceptions amongst groups of individuals and identifying areas for future research. For parents, developing an understanding of their child's AS is complex and this is reflected in the diverse views and perceptions expressed by the caregivers in this study. By no means exhaustive, the current study identified four different accounts by which caregivers' perceive their child's AS. Future research should use the application of Q to identify the narratives of children and young people with AS. This may prove particularly valuable for services when helping families work towards a shared understanding of the disorder. The patient and family perspective is key to the development of health services and, given the increasing number of referrals of children with AS to health services (Steifel et al., 2008), a better understanding of how the family make sense of the disorder is of particular importance.

Declaration of interests

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